

Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids

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When provided by a skilled, multidisciplinary team, palliative care is highly effective at addressing the physical, psychological, social, and spiritual needs of dying patients and their families. However, some patients who have witnessed harsh death want reassurance that they can escape if their suffering becomes intolerable. In addition, a small percentage of terminally ill patients receiving comprehensive care reach a point at which their suffering becomes severe and unacceptable despite unrestrained palliative efforts; some of these patients request that death be hastened. This paper presents terminal sedation and voluntary refusal of hydration and nutrition as potential last resorts that can be used to address the needs of such patients. These two practices allow clinicians to address a much wider range of intractable end-of-life suffering than physician-assisted suicide (even if it were legal) and can also provide alternatives for patients, families, and clinicians who are morally opposed to physician-assisted suicide. This paper will define the two practices, distinguish them from more standard palliative care interventions and from physician-assisted suicide, illustrate them with a real clinical scenario, provide potential guidelines and practicalities, and explore their moral and legal status. Although medicine cannot sanitize dying or provide perfect answers for all challenging end-of-life clinical problems, terminal sedation and voluntary refusal of hydration and nutrition substantially increase patients' choices at this inherently challenging time.

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Palliative care, which addresses the multiple physical, psychosocial, and spiritual dimensions of suffering, should be the standard of care for the dying (1–5). Such care is usually effective (6–12), but some patients develop intolerable suffering despite excellent care (13–17). This paper discusses terminal sedation and voluntary refusal of hydration and nutrition as potential last-resort responses to severe, unrelievable end-of-life suffering. As part of their palliative care skills and services, clinicians must have strategies for responding to the troubling problems of patients who experience such suffering. These two options provide a means of response for patients, families, and clinicians who oppose physician-assisted suicide.

Case Presentation

BG was a 66-year-old retired radiologist who developed a large glioblastoma in the left parietal lobe. After extensive discussion, he elected to pursue a purely symptom-oriented approach. BG was married with two grown children. He was a proud, independent person who valued his intellectual abilities and physical integrity. He was a lifelong Unitarian. From his experience as a radiologist, he knew the natural history and potential burdens of aggressive treatment of similar brain tumors. He did not want to die but was fearful of becoming physically dependent and intellectually impaired.

The treatment goal was to manage his symptoms so that he could have quality time with his wife and children. Dexamethasone and antiseizure medications were the central symptom-relieving measures. Initially, his right-side weakness and headache improved for several weeks as he and his family worked to achieve closure in their lives together.

Unfortunately, BG abruptly developed right-side weakness and intermittent confusion secondary to focal motor seizures, and his symptoms steadily worsened despite treatment. Sensing his physical and intellectual deterioration, BG wanted to “get on with it before I can’t do anything for myself.” Further mental and physical deterioration became more frightening to him than death. He hoped he could die quickly by

stopping corticosteroid therapy. BG's physician urged him to continue his medications for symptom relief, but BG did not want to take anything that could in any way prolong his life. At his internist's insistence, BG agreed to a single visit with a psychiatrist, who confirmed that BG understood his treatment options and was not clinically depressed. After saying his good-byes to friends and family, BG discontinued dexamethasone therapy.

To BG's consternation, he did not become comatose or die. Instead, his right-side weakness worsened and his seizures became more frequent. BG found his situation intolerable. He did not explicitly request medication that could be taken in a lethal dose, but his desire for a hastened death was clear. "I just want to go to sleep and not wake up," he said.

All members of the team were committed to relieving his distress but had different views about explicitly assisting death. They searched for common ground while continuing to adjust his seizure management, support his family, and bring some quality to his days. None of their efforts changed BG's certainty that he did not want to continue living under his current circumstances. He began to consider refusing all food and fluids and asked his physician what it would be like and whether she would support him.

The Clinical Problem

Comprehensive palliative care is highly effective (6–12), but survey data show that 5% to 35% of patients in hospice programs describe their pain as "severe" in the last week of life and that 25% describe their shortness of breath as "unbearable" (15). On occasion, such symptoms as delirium, bleeding, weakness, open wounds, profound weight loss, and seizures challenge the most experienced hospice teams.

In terminally ill persons, requests for physician-assisted death are infrequently triggered by unrelieved pain alone but more commonly result from a combination of physical symptoms and debility, weakness, lack of meaning, and weariness of dying (18–21). Some of these patients are clinically depressed, and others are not (22–25). Usually, their suffering is a complex amalgam of pain; physical symptoms; and psychosocial, existential, and spiritual issues, which are balanced by hope, love, connection, and meaning (26–30). Understanding each patient's unique situation and responding to it in a multifaceted way is the crux of palliative medicine. Suffering can arise from a sense of impending disintegration of one's person (26) or a loss of meaning (27) that may have little to do with uncontrolled physical symptoms.

BG feared becoming a burden to his family and developing progressive loss of mental capacity more than he feared uncontrolled pain. He had no moral reservations about hastening death under his current circumstances. For him, the humaneness and effectiveness of the intervention were more important than whether it required his physician's "active" or "passive" assistance. His physician had moral and legal reservations about hastening death but was deeply committed to BG's comfort and wanted to be responsive to the dilemma that he faced.

Definition of the Practices

Terminal Sedation

Terminal sedation is the use of high doses of sedatives to relieve extremes of physical distress. It is not restricted to end-of-life care and is sometimes used as a temporizing measure in trauma, burn, postsurgical, and intensive care. Although rendering a patient unconscious to escape suffering is an extraordinary measure, withholding such treatment in certain circumstances would be inhumane. Because most of the patients who receive heavy sedation are expected to recover, careful attention is paid to maintaining adequate ventilation, hydration, and nutrition.

When applied to patients who have no substantial prospect of recovery, terminal sedation refers to a similar last-resort clinical response to extreme, unrelieved physical suffering (14, 31–36). The purpose of the medications is to render the patient unconscious to relieve suffering, not to intentionally end his or her life (37). However, in the context of far-advanced disease and expected death, artificial nutrition, hydration, antibiotics, mechanical ventilation, and other life-prolonging interventions are not instituted and are usually withdrawn if they are already in place. These measures are withheld during terminal sedation because they could prolong the dying process without contributing to the quality of the patient's remaining life. In the context of end-of-life care, the component practices of intensive symptom management and withholding life-sustaining treatment have widespread ethical and legal support (31, 38–40). However, because death is a foreseeable, inevitable outcome of the aggregated circumstances of the patient's condition and interventions, the act can be more morally complex and ambiguous than is often acknowledged (31, 40–43).

Terminal sedation should be distinguished from the common occurrence of a dying patient gradually slipping into an obtunded state as death approaches; this occurrence is a combination of the meta-

bolic changes of dying and the results of usual palliative treatments. Terminal sedation is also distinct from the sedation that occasionally occurs as an unintended side effect of high-dose opioid therapy, which is used to relieve severe terminal pain (37). In contrast, terminal sedation involves an explicit decision to render the patient unconscious to prevent or respond to otherwise unrelievable physical distress. Terminal sedation is also used regularly in critical care practice to treat symptoms of suffocation in dying patients who are discontinuing mechanical ventilation (44).

Voluntary Cessation of Eating and Drinking

In the context of far-advanced illness, a competent patient can consciously choose to refuse food and fluid (31, 45–48). When a patient who is still capable of eating and drinking makes this decision with the intention to hasten death, it can be distinguished from the natural anorexia and loss of thirst that frequently accompany the end stages of dying. Some consider such decisions to be a form of suicide (31). However, because such patients view continued eating and drinking as measures that prolong life without value, others argue that the decision to stop eating and drinking can be categorized as a decision to forgo life-sustaining therapy (45–48). The patient's decision to refuse food and fluids has the ethical advantage of being neither physician ordered nor directed. In practice, however, honoring the decision requires the support of the family, physician, and health care team, who must provide appropriate palliative care as the dying process unfolds.

During food and fluid fasts, any uncomfortable emerging symptoms will need palliation. In the context of advanced oncologic illnesses, hunger is rare and transient and symptoms of dry mouth and throat usually respond to assiduous mouth care (49). Dying under these circumstances can take several days to a few weeks, depending on the patient's disease burden and nutritional and metabolic state at the outset. Doubts on the part of the family or physician may arise as the process unfolds, especially if the process is prolonged or the patient develops preterminal delirium. If in the context of a subsequent period of confusion or delirium the patient persistently calls out for a specific food or beverage, it is reasonable to offer it. If such requests persist, the overall plan should be reevaluated. If a patient becomes severely agitated as death approaches, intensive symptom management, including terminal sedation, may be indicated to ensure comfort.

Moral and Legal Status

Although legal precedents guiding terminal sedation and cessation of eating and drinking are less developed than those involving other end-of-life decisions, the June 1997 U.S. Supreme Court decision on assisted suicide suggested that these practices are permitted under current law (50–52). The Court unequivocally supported the patient's right to refuse treatment, even if the intention is to hasten death, on the basis of the patient's right to bodily integrity. Furthermore, Justices O'Connor and Souter each wrote a concurrence supporting the use of medication to alleviate the pain and suffering of terminally ill patients, even to the point of causing unconsciousness or hastening death (51, 52).

Public and professional discussion of these practices is now under way (31, 37–42, 48, 53). In Supreme Court briefs opposing physician-assisted suicide, hospice, palliative care, and geriatric groups stated that terminal sedation and cessation of eating and drinking were morally and clinically preferable last-resort alternatives because death is not directly or intentionally hastened by the physician (54, 55). In addition, in the context of advanced disease, sedation and patient refusal to eat and drink can be used to respond to a much wider range of clinical circumstances than physician-assisted suicide, even if the latter were legal. Both sedation and refusal to eat and drink can be undertaken and supported within usual health care settings.

However, several challenging moral questions remain. Are these practices fundamentally different from physician-assisted suicide? An in-depth comparison of these last-resort options has been presented elsewhere (31, 48). Some clinicians, patients, and families believe that the differences between such practices and assisted suicide are fundamental (39, 41, 42, 48, 53). For others, all such practices, including assisted suicide, are more similar than different (31, 37, 40). Many who believe that physicians should never intentionally hasten death consider terminal sedation the end of the continuum of symptom management. Because voluntary cessation of eating and drinking is by definition a patient decision, the clinician's role is one of continued care and support. Conversely, a clinician who counters a patient's decision by forcing food or artificial nutrition and hydration risks committing assault. Many clinicians may find that these options provide morally acceptable ways to respond to severe terminal suffering without violating their consciences or abandoning the patient.

When a patient stops eating and drinking to hasten death, is clinical support for the decision equivalent to assisted suicide? The moral evaluation of clinical practice in these situations depends in part

Table 1. General Guidelines for Terminal Sedation and Voluntary Cessation of Eating and Drinking

Guideline Domain	Terminal Sedation	Voluntary Cessation of Eating and Drinking
Palliative care	Must be available, in place, and unable to adequately relieve current suffering	Must be available, in place, and unable to adequately relieve current suffering
Usual patient characteristics	Severe, immediate, or otherwise unrelievable symptoms (for example, pain, shortness of breath, nausea, vomiting, seizures, delirium) or to prevent severe suffering (for example, suffocation sensation when mechanical ventilation is discontinued)	Persistent, unrelenting, otherwise unrelievable symptoms that are unacceptable to the patient (for example, extreme fatigue, weakness, debility)
Terminal prognosis	Usually days to weeks	Usually weeks to months
Patient informed consent	Patient should be competent and fully informed or noncompetent with severe, otherwise irreversible suffering (clinician should use advance directive or consensus about patient wishes and best interests)	Patient should be competent and fully informed
Family participation in decision	Clinician should strongly encourage input from and consensus of immediate family members	Clinician should strongly encourage input from and consensus of immediate family members
Incompetent patient	Can be used for severe, persistent suffering with the informed consent of the patient's designated proxy and family members. If no surrogate is available, team members and consultants should agree that no other acceptable palliative responses are available	Food and drink (oral food and fluids) must not be withheld from incompetent persons who are willing and able to eat
Second opinion(s)	Should be obtained from an expert in palliative care and a mental health expert (if uncertainty exists about patient's mental capacity)	Should be obtained from an expert in palliative care, a mental health expert, and a specialist in the patient's underlying disease (strongly advised)
Medical staff participation in decision	Input from staff involved in immediate patient care activities is encouraged; physician and staff consent are required for their own participation	Input from staff involved in immediate patient care activities is encouraged; physician and staff consent are required for their own participation

on their clinical context. For a patient with anorexia nervosa, clinical depression, or mildly symptomatic illness, cessation of eating and drinking would be considered a form of suicide that should be prevented by appropriate interventions. In contrast, for a patient with severe, unrelieved suffering and advanced, incurable illness, cessation of eating and drinking might be considered part of the right to refuse treatment (31, 48, 53).

Some clinicians and ethicists, however, consider any and all intentional hastening of death by a patient to constitute suicide, making physician support of such choices unacceptable. An absolute stance of this nature creates a double bind for patients who are ready for death and desire the continued help of their physician. If such patients are honest about their intention, their request for physician support cannot be granted. To maintain a therapeutic relationship and be guaranteed continued symptom management, they and their families may have to collude in a deception and conceal their decision to stop eating and drinking.

Are physicians required to support requests for these practices? All physicians should fully explore patient requests for terminal sedation or inquiries about voluntary cessation of eating and drinking to ensure that they are not emanating from unrecognized depression or symptoms that may respond to palliative measures (56, 57). However, physicians should not be required to participate in these processes if doing so violates their fundamental moral precepts (31). If physicians cannot find common ground with a patient, they have a responsibility to obtain palliative care or ethics consultations and to transfer care to more receptive physicians.

Additional unanswered questions provide sub-

jects for future research, description, and discussion. How frequently will sedation or refusal of food and drink be needed in the context of state-of-the-art palliative care? How acceptable will either of these possibilities be to patients, families, and health care providers? Will predictable availability of these last-resort options diminish patients' fears that their physicians will not respond to severe terminal suffering or lessen public interest in assisted suicide? Will discussion of these options make some patients feel pressured or more fearful about physician power and potential abuse? If care of this nature were predictably available, how many patients would still prefer assisted suicide and how many physicians would still covertly break the law by providing assistance? Do patients, families, and physicians see these actions as morally different from physician-assisted suicide or euthanasia? If voluntary cessation of eating and drinking is considered a variation of forgoing life-sustaining treatment, should it be made available to incurably ill and suffering patients whose conditions are not imminently terminal?

Clinical Guidelines

The published guidelines for terminal sedation and voluntary cessation of eating and drinking are summarized in **Table 1** (31, 33). Informed consent, which includes assessing the patient's capacity to comprehend the treatment and the available alternatives, is one cornerstone of these guidelines (56, 57). Clinicians should carefully screen terminally ill patients for clinical depression because it is extremely prevalent and can be difficult to diagnose (24–28). Although full decision-making capacity is

an absolute requirement for voluntary cessation of eating and drinking, terminal sedation may sometimes be needed in acute symptomatic emergencies when the dying patient cannot respond. In such severe circumstances, family members, consultants, and other members of the health care team may have to represent the patient's values.

A second cornerstone is the presence of severe suffering that cannot be relieved by other available means. The main indication for terminal sedation is usually severe, uncontrolled physical suffering, such as intractable pain, dyspnea, seizures, or delirium. Patients who have more unrelenting, persistent, unacceptable symptoms, such as extreme fatigue, weakness, or debility, may consider refusing food and fluids. If either option is being considered by clinicians, patients, or families when the suffering person is not imminently dying, assessments should always include second opinions from mental health, ethics, and palliative care specialists.

These guidelines represent the minimum requirements for these measures. Terminal sedation should be used only in the most difficult cases, which are typically marked by intense discussion of the clinical and ethical issues on the part of the physician, the clinical team, the family, and the patient. Similarly, a patient's decision to stop eating and drinking must include thorough evaluation for depression and spiritual suffering and assiduous clarification of motives and alternatives with the patient, family, and professional caregivers. The struggle experienced by the clinical team involved with these cases is a mark of the authenticity of care and contributes to the moral acceptability of the choices made.

Clinical Practicalities

In response to BG's decision to stop eating and drinking, his physician discussed the likely clinical course and the symptoms he would experience. She promised to use medications for sedation if his suffering became intolerable during the dying process. His physician reassured him that the process was usually comfortable and that together they would address any discomfort that arose. BG felt liberated by having made a choice that he could openly pursue at his own volition. Two weeks would probably pass between the decision to refuse food and fluids and death, but BG did not view this prospect as an excessive burden. It would allow him some time to again say good-bye to his family, but with a predictable beginning, middle, and end. BG discussed his decision with his wife, children, and minister and the psychiatric consultant.

All severely ill patients who experience substantial suffering and have a poor prognosis should be informed about the potential of palliative care to

address their symptoms (58, 59). However, it would be burdensome and inappropriate to discuss these last-resort options with all patients who have late-stage illness. Information about terminal sedation and cessation of eating and drinking becomes important when patients express fears about dying badly or explicitly request a hastened death because of unacceptable suffering (56, 57). Such information must be presented with sensitivity, however, because some patients may consider discussion of these options coercive, potentially requiring them to justify a decision to continue living. Other patients may find the prospect of spending their final days in an iatrogenic coma to be meaningless and undignified and may prefer a more decisive action, such as assisted suicide.

BG stopped eating and drinking. The initial week was physically comfortable and personally meaningful. BG's family shared stories, played cards, and listened to music. BG took antiseizure medications with sips of water but absolutely nothing else orally. Morphine by continuous subcutaneous infusion at an initial dosage of 1.0 mg/h controlled his headaches without causing sedation. His mouth was kept moist with ice chips and swabs, but he was careful not to swallow any of the liquid. After 9 days, he could be roused but spent most of the day and night sleeping.

Although the patient's refusal of food and fluids technically does not require the physician's participation, a physician should be part of the team who assesses the patient's request and provides palliative care as the process unfolds. Therefore, physicians who oppose their patient's decision from the outset must decide whether they can provide all forms of indicated palliation. If the physician feels morally unable to do so, transfer of care to another provider should be considered.

On day 10, BG became confused and agitated and began having hallucinations. The peace and comfort that he and his family had achieved began to unravel. BG was now incapable of informed consent but had previously given permission for sedation if this problem arose. After discussions with his family, BG was started on a low-dose subcutaneous infusion of midazolam for treatment of seizures and agitation. The plan of care was to use whatever dose was required to control seizures and agitation. The initial dosage was 0.5 mg/h, with bolus doses of 0.5 to 1 mg ordered up to every 15 minutes as needed. The option of transferring BG to an inpatient unit was explored, but the family preferred to keep him at home. Around-the-clock home nursing was arranged under the "continuous care" provision of the Medicare hospice benefit program. After several bolus doses and adjustment of the infusion to 2.5 mg/h during the first 6 hours, BG seemed to be sleeping comfortably. No attempt was made to restore consciousness, and no further in-

Table 2. Medications Used for Terminal Sedation*

Medication	Type	Usual Starting Dosage	Usual Maintenance Dosage	Route
Midazolam	Rapid, short-acting benzodiazepine	0.5–1.5 mg/h after bolus of 0.5 mg	30–100 mg/d	Intravenous or subcutaneous
Lorazepam	Benzodiazepine	1–4 mg every 4–6 h orally or dissolved buccally; infusion of 0.5–1.0 mg/h intravenously	4–40 mg/d	Oral, buccal, subcutaneous, or intravenous
Propofol	General anesthetic; ultrarapid onset and elimination	5–10 mg/h; bolus doses of 20–50 mg may be administered for urgent sedation, but continuous infusion is required	10–200 mg/h	Intravenous
Thiopental	Ultrashort-acting barbiturate	5–7 mg/kg of body weight to induce unconsciousness	Initial rate may range from 20 to 80 mg/h; average maintenance rates range between 70 and 180 mg/h	Intravenous
Pentobarbital	Long-acting barbiturate	2–3 mg/kg, slow infusion, to induce unconsciousness	1 mg/h, increasing as needed to maintain sedation	Intravenous
Phenobarbital	Long-acting barbiturate	200 mg loading dose, repeated every 10–15 minutes until patient is comfortable	Approximately 50 mg/h	Intravenous or subcutaneous

* Adapted from references 32, 33, and 60–64. Goal of treatment is to relieve suffering by inducing sedation. Dosage should be increased by approximately 30% every hour until sedation is achieved. Once desired level of sedation is achieved, infusion is usually maintained at that level as long as the patient seems comfortable. If symptoms return, dosages should be increased in 30% increments until sedation is achieved. The ranges above are representative. Individual patients may require lower or higher doses to achieve the desired goal. Previous doses of opioids and other symptom-relieving medications should be continued.

creases in medication were needed to maintain sedation.

In the context of advanced illness and imminent death, sedation can be achieved with a barbiturate or benzodiazepine infusion, which should be rapidly increased until the patient is adequately sedated and seems comfortable. A level of sedation that eliminates signs of discomfort (such as stiffening or grimacing spontaneously or with routine repositioning and nursing care) is maintained until the patient dies. **Table 2** shows potential starting dosages and strategies for increasing dosages and monitoring. Depending on the severity of the patient's physiologic condition at the onset of the procedure, the interval from initiation to death is usually hours to days. Continuous sedation usually requires a subcutaneous or intravenous infusion and intensive involvement by the health care team for observation, monitoring, and support. When a dying patient requires sedation, opioids for pain and other symptom-relieving measures should also be continued to avoid the possibility of unobservable pain or opioid withdrawal. However, opioids are generally ineffective at inducing sedation and are not the medications of choice.

Conclusion

BG died quietly approximately 24 hours later in his home, surrounded by his family. BG's family had remained resolute in their support for his decision and firmly committed to keeping him at home. However, they also continued to have emotional family discussions and at times struggled with whether they had done too little or too much to help him die peacefully.

They drew comfort from recognizing that they had kept BG's values in the forefront and made the best of a potentially devastating situation.

Medicine cannot sanitize dying or provide perfect solutions for all clinical dilemmas. When unacceptable suffering persists despite standard palliative measures, terminal sedation and voluntary refusal of food and fluids are imperfect but useful last-resort options that can be openly pursued. Patients and their families who fear that physicians will not respond to extreme suffering will be reassured when such options are predictably made available (65). Relevant professional bodies can help by adopting policy statements that attest to the ethical and professional acceptability of these components of palliative care.

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